

SECTION 2

Developing a Better Understanding of Disabilities and Functional Abilities

Introduction

The previous section of this workbook provided information about the regulatory criteria for ADA paratransit eligibility. It included the actual regulatory language as well as explanatory text from the “interpretive” appendix to the USDOT’s ADA regulations.

This section of the workbook provides additional guidance for understanding the travel abilities of persons with disabilities. It suggests sources of information that can be used to gain an understanding about various disabilities and health conditions. It also suggests how general information about a type of disability or health condition can be used to develop appropriate follow-up questions needed to gain a full understanding of the functional ability of applicants. A sample case study is offered to illustrate how to proceed from a general understanding of disability to a specific understanding of the abilities that affect use of fixed route transit.

Some common misperceptions about travel abilities are also discussed. This includes misunderstandings about how the use of certain mobility aids affect travel. It also includes thoughts on path-of-travel barriers that are not always obvious.

Public perceptions about the accessibility and usability of public transit services are also noted. While they are not factors in determining actual functional ability, they represent an attitude and history that is important to understand.

Using fixed route transit requires that an individual be able to execute and coordinate a complex combination of physical, cognitive and sensory tasks and cues. An individual with a disability, by definition, has one or more significant limitations, and as with many tasks encountered in his or her daily life, must develop an adaptive strategy to complete the task. Strategies include the use of equipment or mobility aids, and training that teaches new methods to navigate the environment. These methods and tools vary between individuals, as does individual, personal travel ability. In order to give full consideration to the range of abilities necessary, it is important to begin with an understanding of the effect that a disability can have on the functional tasks necessary to use transit.

Ask Your Customers

There is no better way to develop an understanding of the issues that transit users with disabilities face than to talk with them, walk through the community with them, and ride the bus or rail system with them. Spend time using transit with customers with different disabilities and ask for their frank assistance in explaining not only issues they encounter with the transit system, but their personal functional issues as well. Ask questions about things you do not understand, and be open-minded.

Ability – Not Limitation

People with disabilities are often described in terms of their limitations – an attitude that has served to limit the opportunities of people with disabilities to participate fully in the mainstream of life. Just as many paratransit customers have inherent biases about their ability and the accessibility of the environment and the transit systems in our communities, there are many deeply held personal beliefs and assumptions due to a limited or superficial understanding of disabilities.

Frequently, references made to a person with a disability do not refer to the individual at all, and are either in terms of a diagnosis (e.g., Cerebral Palsy) or mobility equipment (e.g., “wheelchair user”). While some broad information can be learned from type of disability or mobility aids used, it tends to describe the individual in a negative way, often adds to the perception that people with disabilities are less able, and defines the person according to a “medical model.” Simply knowing diagnostic information also does not adequately predict how the individual functions.

Not a Medical Model

Knowing the diagnosis can have a place in the eligibility process. A diagnosis can provide some baseline information about the general characteristics of a particular condition, and can help you focus your conversation about barriers on those areas which are most likely to impact the applicant's ability to use fixed route transit independently. However, the applicant must not be reduced to the elements of his or her diagnosis by oversimplification, and reviewers should be careful about not taking on the role of a health care professional. It is not necessary or appropriate for transit staff to apply health care or medical principles to the eligibility decision. When diagnostic information is used only to better understand some of the functional impacts of particular disabilities, it can be a useful tool.

Sources of Information

It is important to have available several good sources of basic information regarding types of disabilities and health conditions. One especially widely used and well respected guide is *The Merck Manual of Medical Information* (also published in a Home Edition, which is written in non-medical language that is easily understood by the average reader.) According to the publication's preface, "*The Merck Manual* is the oldest continuously published general medical text book in the English language, and the most widely used medical textbook in the world."⁴ It covers almost every disease and special situation that affect humans, from injuries to complicated medical conditions.

The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) published by the American Psychiatric Association is the definitive classification of "mental disorders" and is the main diagnostic reference of mental health professionals in the United States. It includes explicit diagnostic criteria and uses a descriptive approach for every condition listed in its pages.

"Mental disorder" is defined in this document as "a clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and is associated with present distress, disability, or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom. In addition, this syndrome or pattern must not be the effect of an expectable and culturally sanctioned response to a particular event, such as the death of a loved one."⁵ The introduction makes it clear that the *DSM-IV* does not categorize people, but rather the disorders that people have.

This manual provides a starting point to better understand the particular characteristics of schizophrenia and other psychotic disorders, developmental cognitive disabilities, anxiety disorders, mood disorders (such as Bi-Polar Disease) and personality disorders, to name a few.

⁴ The Merck Manual of Medical Information, Home Edition, Merck & Co., Inc., 1997.

⁵ DSM-IV, American Psychiatric Association, 1994.

The DSM-IV is used by the medical profession as a diagnostic tool, along with clinical judgment and experience. It outlines the specific criteria with defining features that an individual who carries that diagnosis will be likely to have. It is written and designed for use by individuals with clinical training and experience. The introduction bears the following warning: “It is important that *DSM-IV* not be applied mechanically by untrained individuals. The specific diagnostic criteria...are meant to serve as guidelines...and are not meant to be used in a cookbook fashion.” In other words, it would be a dangerous error to assume that after reading the description of the general characteristics of a particular condition in the *DSM-IV* you will have a full understanding of the impact the condition has on an individual. What you can learn is the range and extent of functional limitations that individuals with the disability may experience.

For example, if you are preparing to talk with an applicant who has presented a diagnosis of recurrent unexpected Panic Attacks, if you consult the *DSM-IV*, you will learn:

- The individual has recurrent panic attacks which are not expected.
- For at least one month he has done at least one of the following:
 - Worry that there will be more attacks
 - Worry about what the attacks mean (health problems, etc.)
 - Significantly change behavior, such as doing something to avoid the attacks.
- The panic attacks are not directly caused by another medical condition, or the use of substances, including medication

You will read more about the characteristics of panic attacks:

- They may occur by themselves or in connection with other conditions
- They are common
- They can often be treated
- Untreated, they can be severely debilitating
- They may mask other illnesses
- They may be triggered by a specific situation, or may occur without pattern or warning

You will learn that the criteria for panic attacks include:

- The individual will suddenly develop a severe fear that peaks within 10 minutes
- During this 10 minutes, the individual will experience four or more of the following:
 - Chest pain
 - Chills or hot flashes
 - Choking sensation
 - Dizzy, faint, lightheaded or unsteady feelings
 - Fear of dying
 - Fear of loss of control
 - Heart pounding, racing or skipping beats
 - Nausea
 - Sweating
 - Numbness or tingling

- Shortness of breath or smothering sensation
- Trembling

Now you have a baseline of information that gives you a foundation for developing and asking good relevant follow up questions of the applicant and perhaps of professionals involved in his treatment.

The DSM-IV is written for professionals and, as such, can be difficult to read and understand. There are several guides to the DSM-IV that are written in clear language, are less technical, and include case studies to illustrate specific situations and conditions. One that is especially useful is ***DSM-IV Made Easy*** by James Morrison.

The Merck Manual, the Merck Manual Home Edition, DSM-IV and other guides such as ***DSM-IV Made Easy*** are all available at any bookstore or on-line from booksellers such as www.amazon.com. The 17th ***Edition of The Merck Manual*** is also available free on-line for your use – go to www.merck.com/pubs/mmanual. This web site also has a link to the ***Merck Manual Home Edition*** which is also available for use on-line, free!

Portions of the ***DSM-IV*** are also available for use on line, but the complete publication is not. The easy to use web site is www.psychologynet.org/dsm.html.

Many national service organizations also maintain web sites which are excellent sources of information. They are also a good way to locate local chapters of service agencies in your community. To learn more about epilepsy, for example, you can start with reading more in the ***Merck Manual*** about the many types of seizures and the range of functional limitations that individuals typically experience as a result. You can then visit the web site for the Epilepsy Foundation of America at www.efa.org. Not only will the web site provide more information which is less medical in nature, but it will help you locate the local affiliate. Then you can schedule a meeting to talk with staff and consumers at the Epilepsy Foundation, where they will be happy to help you learn more. These organizations typically share our goal – to support people with disabilities and health conditions in their daily life, and to assist them in maintaining the highest personal functioning level possible. Part of their mission usually also includes educating the general public about the condition and eliminating misconceptions and stereotypes.

A word of caution regarding Internet sites – be sure that the site you have chosen has a national reputation and is reliable. The Appendix for the ***Merck Manual Home Edition*** contains a good list of web sites that represent national not-for-profit and governmental service agencies. You can also get more information from Project ACTION.

Case Study: Learning Something From a Diagnosis

A condition that applicants for ADA paratransit cite with increasing frequency is diabetes. Having the diagnosis of diabetes, by itself, does not constitute a disability. It is the effect of the many complications of diabetes that can result in disability. By reading more about diabetes, you can learn that there are several types of diabetes, the most severe of which is Type I (insulin dependent) diabetes. Some of the most common long-term complications of this disease include:

- Poor circulation, which can cause wounds to heal slowly, can lead to infection, stroke and heart disease;
- Decreased vision and sometimes blindness, due to the damage caused to the small blood vessels of the retina (diabetic retinopathy);
- Kidney failure (which can result in dialysis);
- Damage to nerves which results in weakness of the legs and reduced sensation in the hands and feet;
- Swings in blood pressure; and
- Diabetic ulcers.

Your applicant states that she has diabetes, and the medical information states that she has severe “chronic polyneuropathy” as a result. You determine that the applicant has Type I Diabetes by asking her if she must use insulin. You know that neuropathy is a common complication of individuals with diabetes, and you read more to learn that neuropathy commonly results in the following:

- Numbness, and an inability to sense vibrations or the position of the arms, legs and joints;
- Pain, often aggravated by temperature changes;
- Skin ulcers or other injuries from prolonged pressure (since the individual may not be able to feel her feet or legs, or sense changes in temperature.);
- Slow healing of a wound, due to poor blood supply to the skin. Foot ulcers may become deep and infected, and can sometimes result in amputation.
- Changes in gait pattern and abnormal weight bearing
- Development of Charcot’s Joints which result from nerve damage that impairs a person’s ability to feel pain coming from a joint. As a result, injuries and fractures often go unnoticed and can cause long term damage to the joint.

With this baseline information in hand, you can proceed to focus on functional travel issues that are likely to be most limiting for the individual:

- Without sensation in the feet, it is likely that balance will be poor, and the individual may be unsteady while walking, or even standing. Additional difficulty could be anticipated when walking over uneven surfaces, or if recovering from being bumped, either on a crowded bus or sidewalk.
- If sensation in the hands has also been affected, the use of mobility aids might be limited as a result.

- If pressure injuries have been a problem, the individual may no longer be able to wear a prosthetic device – temporarily or permanently.
- If there is also an indication of a vision problem (which is likely), the applicant may not be able to rely on visual cues to aid foot placement and balance. Even though the medical information may not state that the applicant has vision limitations and the applicant may not mention it, you know that it is likely to be an issue for which you should pay particular attention in the interview and assessment.

Although this background, by itself, is not sufficient for you to determine whether the extent of the applicant's condition would prevent her from using the bus, it will help you direct specific follow up questions in the interview, and focus on particular elements of the functional assessment and follow-up with professionals, if necessary. It can also help you confirm whether performance appears to be consistent with the stated disability, or whether additional follow-up questions are necessary.

It is equally dangerous to rush to an assumption that technology and sophisticated equipment, such as the use of a particular mobility aid, or completion of training eliminates all of the barriers to independent travel within the community. Everyone who uses a power wheelchair is not automatically able to overcome every environmental barrier – the person must first have the functional ability to safely operate the power wheelchair throughout the community.

If the above case study were changed to an individual who has recently acquired a power wheelchair, it may be because she has severe neuropathy in both the hands and feet, preventing her from using a walker, or pushing a manual wheelchair. The use of a power wheelchair makes it possible for her to navigate familiar settings such as her home, church and local market with relative ease, but her failing vision makes it difficult for her to assess uneven surfaces, and she experiences frequent periods of light-headedness and dizziness from her fluctuating blood pressure. She cannot tolerate cold weather, and cannot feel how much pressure she is exerting on the joy-stick of her wheelchair, making it difficult for her to control the speed and execute turns in tight spaces.

While the use of the power wheelchair has made many aspects of her life easier, it does not, by itself, improve her functional ability to the point where she can use fixed route transit independently.

Case Study #2

Another applicant presents information that he has sustained a head injury as a result of an accident. He visits your office and appears to have no problems with gait or balance, and is fairly articulate. He presents medical information that says that he has experienced temporal lobe damage.

You read that the temporal lobe of the brain processes events into long term and short term memory, and people with this type of injury frequently experience amnesia. You read further to learn that three types of memory can be affected by amnesia:

Immediate memory – recall of events that happened in the preceeding few seconds

Intermediate memory – recall of events that happened a few minutes to a few days ago

Long-term memory – recall of events from longer ago

This amnesia can be temporary or permanent.

Learning requires memory. If the applicant has learned the essentials of using fixed route transit many years ago, and his memory loss is more immediate or intermediate he may remember how to board the bus, pay the fare, plan a trip, etc. However, there are many immediate memory considerations for using fixed route including route finding. You can now prepare some follow up questions for the applicant and professionals directed at the specific functional areas where you can reasonably expect the applicant to have difficulty.

Imagine getting ready to leave for an appointment you made yesterday. You remember how to dress, prepare breakfast and leave the house. You get outside the house a short distance from home and cannot remember where you are going, or the reason for your trip. You carry many assistive devices with you (note cards, a calendar, written directions,) but you find yourself so confused, you do not even remember that you carry these tools in your pocket. In order for the travel aids to be useful, you must remember that you have them when you need to use them! You may have difficulty seeking help since you cannot remember your destination or the purpose of your trip.

In addition to the functional questions you will ask the applicant during the interview, follow up questions to professionals could include the date of onset and prognosis for the individual.

Environmental Barriers

An individual with a disability who is able to negotiate the environment may still encounter environmental barriers. There is an extensive discussion of barriers that may impact a traveler with a visual disability in Chapter 7. Others are easy to identify, such as the lack of a curb cut or several inches of snow for a individual using a wheelchair. Some are more subtle, but no less problematic.

When is a Sidewalk not a Sidewalk?

There are many cities with very old infrastructures, including old sidewalks which are sometimes less than 32” wide. It is not impossible for the user of a scooter, for example, to discover that her wheelchair is in danger of falling off the curb if she must turn even an inch to avoid a barrier, or even another pedestrian. The only alternative available in such situations is to travel in the street, clearly a dangerous option.

Sidewalks can also have significant cross slopes – often when designed to angle away from the building to prevent water from accumulating. They are not supposed to exceed a certain slope as established in the ADAAG. However, just as all curb ramps are not installed properly and according to ADA minimum specification, it is not unusual to find sidewalks, particularly in older cities, which have a severe cross slope. This can be a particular problem for the user of a manual wheelchair who will have to exert considerably more effort with his “downhill” arm to keep from rolling into the street. This requires strength, and if the slope continues for any distance, strength and endurance which may be beyond the functional ability of the individual.

Extremes of Temperature

Seasonal eligibility, which has become increasingly popular as an easy to implement condition of eligibility, is usually designed to reflect the time of the year when conditions of extreme heat, cold or snow are most likely to occur. Since seasonal eligibility is usually supposed to reflect a temperature range, it is important to understand the exact range and the resulting impact on the traveler with a disability.

For example, depending on the extent and location of the injury, an individual with a spinal cord injury may have lost the ability to regulate his body temperature adequately. Certain levels of spinal cord injuries render the individual unable to perspire below the area of the spinal cord that was damaged. Perspiration is one of the primary ways in which our bodies control internal temperature.

The individual’s eligibility may be for trips between June 15 and September 15, designed to predict those days when it is most likely to be very hot. However, when the inevitable 90 degree day occurs on May 28, the individual will not be able to stay outdoors for a prolonged period of time without experiencing a potentially dangerous rise in his body temperature.

Travelers with disabilities should be able to count on the flexibility of the paratransit system to implement the true conditions of eligibility that accurately reflect the environmental barrier. Exposure to extreme heat (generally over 85 degrees, especially when combined with high humidity) is not an issue of comfort or convenience for this traveler, but could be life-threatening. Although the individual will usually employ strategies to promote cooling, wearing a hat and protective clothing will not provide adequate protection for this traveler from extremes of heat for very long, and your understanding of the environmental condition combined with the traveler's particular disability is essential.

These examples, and others you will learn from your customers with disabilities, illustrate the complexity of the environment in which people must travel and the need to be aware of such barriers and make sure they are reflected in conditions of eligibility when appropriate.

Perceptions About Transit Access

Strictly speaking, people's feelings and beliefs about transit are not factors that should be considered in an ADA eligibility decision. They do help to form, however, the perception that many people have of the accessibility of public transit and the lack of pedestrian access in our communities. These perceptions certainly can have an impact on an applicant's self-assessment of the level of effort necessary to use the bus. Transit has made great strides over the past decade, but understanding the history and development of accessible public transportation is important in combating misconceptions and planning for the future. Unfortunately, many of our transit systems have not historically been welcoming to people with disabilities, which has resulted in the common belief that they are not usable, and that paratransit service provides a better alternative.

John Hockenberry is an Emmy and Peabody award winning correspondent for National Public Radio, ABC and NBC News. He also happens to have a disability. In his book ***Moving Violations***, John Hockenberry writes with wit and honesty about many things, including his experiences using public transportation. When reading this excerpt from his book, substitute any city of your choice, since this could be anywhere.

"If you use a wheelchair and you want to avoid cabs in..., you can pay ten thousand dollars a year in parking to have your own car, or you can try your luck at public transit. There are paratransit vans which are bookable far in advance.... And then there are the buses.

The buses in ... have wheelchair lifts, and if the driver is carrying a key to operate the lift, and the lift has been serviced recently, and the bus is not too crowded, and the driver notices you at the stop, then you have a chance of getting a ride... You can ask the driver to put your (fare) into the box, but he will refuse. 'I'm not allowed to touch your money,' is what they usually say, and so they hand you instead a self-addressed stamped envelope to mail a check for a dollar and seventy-five cents to the transit authority. The bus lifts are better than nothing, except that when the city buys new buses, the new wheelchair lifts do not work properly, so there is a period of months when a bus driver drives up and

shrugs and says his bus is one of the new ones. Only in... would the new buses be the ones you can count on not to work.

Attempting to use public transit involves the risk of finding no bus lift, no elevator, or one that will stop working while you are in the middle of using it. The transit system... sometimes seems like an elaborate trap for people in wheelchairs, lured like mice to cheese with promises of accessible transportation.”

He concludes the chapter with his perception of transit as a sort of leveler of humanity, and the vital role that transit plays in our collective mobility.

“The (bus) required only a (fare) to ride, but in each person’s face was the ticket to where they were all really going and the places they thought they never had to leave... Without knowing it, I had left that America behind a long time ago. I discovered it alive and well on the (bus.)”

The most important aspect of understanding travel for people with disabilities is that the basic components are the same for everyone – we all have places to go for which we need to arrive safely and on time. We must be able to afford our ride, and will sacrifice some comfort for a cost saving. We demand the freedom to go where we want to go, when we want to go, and without explaining the reason to anyone. Transportation links us all to our communities, and to life.